

## CreakyJoints Australia Media Release: 12 October 2020

### CreakyJoints Australia Launches New Handbook to Empower Australians With Autoimmune Spinal Arthritis on World Arthritis Day

CreakyJoints Australia launched the inaugural edition of [\*A Patient's Guide to Living with Axial Spondyloarthritis in Australia\*](#) as a free download from their website today to coincide with [World Arthritis Day](#).

This is the first publication of its type to be written by patients specifically for Australians living with axial spondyloarthritis (axSpA) including its subcategories ankylosing spondylitis (AS) and non-radiographic axial spondyloarthritis (nr axSpA).

It is designed as a roadmap to help patients and their caregivers navigate their treatment journey and to access the help they need and deserve.

Neen Monty, a Queensland representative of the CreakyJoints Australia Patient Council, said, *"My first rheumatologist told me how and when to take the medications but he didn't explain how they worked, or why they were important. That journey would have been much easier if I had these patient guidelines. Everything I needed to learn is here now, all in one place in an easy to understand format."*

#### Many Australians Live With AxSpA

There are over 100 different types of arthritis. Osteoarthritis is the most common form, followed by rheumatoid arthritis and gout. Next up is axSpA, though most people have never heard of it.

Axial spondyloarthritis (axSpA) is a form of autoimmune arthritis. It occurs when the immune system mistakenly triggers inflammation and attacks healthy joints and tissues mainly in the spine, hips and the joints on either side of the lower spine that connect it to the pelvic bone.

AxSpA affects males and females roughly equally and usually develops between the ages of 15 and 45 but patients can wait up to 10 years for a correct diagnosis. If axSpA is not diagnosed early or is left untreated or undertreated, the affected joints can deteriorate and potentially fuse, leading to severe functional limitations. AxSpA can also affect organs such as the eyes, bowels and skin and cause debilitating pain and fatigue.

However, axSpA can be well managed with medicinal and non-medicinal therapies. CreakyJoints Australia National Coordinator, Naomi Creek, said, *"Patients living with axial spondyloarthritis can live full and happy lives, but it's vital to get educated about what to expect following diagnosis and over the course of their disease. When armed with an understanding of their condition and all their treatment options, people living with axSpA can make informed decisions about their care in partnership with their healthcare provider team. Empowering the arthritis community to speak up about their preferences and goals for treatment, supported by evidenced-based information, is one of the most important aspects of us launching these guidelines."*

#### About the New Patient Guidelines

***A Patient's Guide to Living with Axial Spondyloarthritis in Australia*** is the second publication in the CreakyJoints Australia 'Raising the Voice of Patients' series of patient guidelines for a range of arthritic conditions.

This unique go-to resource is available as a free download at [creakyjoints.org.au/pg-axspa/](http://creakyjoints.org.au/pg-axspa/).

CreakyJoints Australia encourages all healthcare practitioners with axSpA patients to familiarise

themselves with this resource and to share the link with their patients and through their networks. Free business cards promoting the patient guidelines can be ordered by contacting Ms Creek.

Renowned rheumatologist Professor Paul Bird, Medical Director of [Optimus Clinical Research](#) in Sydney and medical advisor to CreakyJoints Australia, reviewed these patient guidelines prior to publication. Professor Bird says, *“This wonderful resource is accurate and comprehensive. The lack of jargon gives it a simplicity that allows the patient to move through the concepts with ease.”*

Annie McPherson has lived with ankylosing spondylitis (AS) for over 40 years. Annie is a Cofounder and the current President of [Ankylosing Spondylitis Victoria Inc.](#) Ms McPherson said, *“The CreakyJoints Australia team should be commended on their new patient guidelines for axial spondyloarthritis. Along with many daily management tips, they have offered tips for navigating the Australian social services and healthcare systems. This is a well laid out guidebook, supported by references to relevant, up-to-date, and reliable online resources.”*

### **About CreakyJoints Australia**

Founded in 2015, [CreakyJoints Australia](#) is an important source of information for Australian arthritis patients and their families. Our mission is to empower Australians living with arthritis to put themselves at the centre of their own care by talking about their treatment preferences and working in partnership with their healthcare providers.

CreakyJoints Australia connects arthritis patients with current and relevant disease-specific information and support across a spectrum of arthritis conditions, using a diverse set of digital platforms. CreakyJoints Australia provides opportunities for members to proactively advocate for themselves and their families, and to participate in research that will broaden the global understanding of arthritis management.

CreakyJoints Australia is part of the US-based [Global Healthy Living Foundation \(GHLF\)](#), a non-profit organisation whose mission is to improve the quality of life for people with chronic illness.

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### **Notes**

Please use **#CreakyJoints\_Aus** when referring to CreakyJoints Australia on social media and ensure that ‘CreakyJoints Australia’ is punctuated correctly.

You can also use **#WorldArthritisDay**